

Developing a model of disability that focuses on the actions of disabled people, Feb. 2017. 1.**Abstract**

Disabled people, writers on disability and disability activists stress the importance of disabled people being included in all aspects of society. I argue that a major omission from this inclusiveness, is that no current model of disability focuses on the impact of the actions of disabled people on disability. Disabled people are not passive bystanders, powerless to reduce the restrictions of disability. On the contrary, we are central to actively limiting its constraints.

I develop a model of disability, called 'active', which focuses on the effects on disability of the individual and collective actions of disabled people. I describe published findings which indicate that engaging in self-help, using support groups and deploying assistive technology can all reduce the limitations of disability. Recent increases in the number of disability support groups and developments in assistive technology have substantially augmented the potential for disabled people to combat the effects of disability.

Keywords: self-help, support groups, assistive technology, inclusiveness, activism, model of disability.

Points of interest

- This article develops the active model of disability, which focuses on the impact of the actions of disabled people on disability.
- These actions encompass both individual activity (e.g., self-help) and collective activity (e.g., disability activism).
- This model is timely, as the recent increase in the availability of self-help information and support groups has substantially boosted the potential for disabled people to limit the constraints of their own disabilities.
- This article presents published findings that engaging in self-help, using support groups and deploying assistive technology have all reduced the effects of disability.
- It examines the limited role of disabled people in current models of disability and compares the active model with other models.
- Moreover, it argues that both the active and social models can motivate research that improves disabled people's lives (emancipatory research).
- Finally, it contends that the understanding of the complexities of disability can be facilitated, by using multiple, complementary models.

Introduction

The World Health Organisation (WHO) defines impairment as ‘a problem in body function or structure’ and disability as ‘a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives’ (WHO 2017, webpage). Although the WHO’s description of disability implies that both medical and societal factors can affect disability, it does not mention the impact of the actions of disabled people on disability. I argue that the complexity of disability is captured more effectively when it is regarded as reflecting the interaction between features of disabled people’s bodies, society and the actions of disabled people.

I agree with Oliver (1996, 40) that models ‘help us to better understand the world, or those bits of it under scrutiny.’ I contend that the complexity of disability can be understood particularly well, by regarding models of disability as complementary (as opposed to contradictory). I argue that a perspective derived from multiple models can contribute more to this understanding than can a perspective from a single model. I support the stance expressed by Smart (2009, 3): ‘Diversity in models has the potential to be both strengthening and enriching.’

Johnston (1997, 307) proposed a multi-factor perspective of disability, when writing that disability is shaped by ‘physiological, environmental, social, cognitive and emotional factors.’ Although I accept that disability can be affected by the factors suggested by Johnston, I prefer a multi-factor perspective to incorporate the most adopted current models (the social and medical models). Accordingly, I contend that the effects of disability are shaped by a combination of society, the disabling condition, the actions of disabled people, and miscellaneous other factors (e.g., the age of onset of the disability). Moreover, I argue that these components can overlap (i.e., more than one component may concurrently affect a person’s disability), and that the relative impact of each component can vary substantially (between geographical regions, from person to person, and over time in the same person).

In this article I develop the active model of disability, that focuses on the effects of the actions of disabled people on disability, individually (e.g., self-help) and collectively (e.g., activism). In order to empirically ground the model, I examine three ways in which the actions of disabled people can shape their own disabilities: self-help, engaging with support groups and using assistive technology. However, I do not contend that the active model is confined to these components, or even that they are the most significant aspects of this model.

As elaborated in the Background, inclusiveness has been a key concern for disabled people and for writers on disability. I argue that a major omission from inclusiveness, is that no current model focuses on the effects of the actions of disabled people on disability. In this article I seek to address this omission.

My article responds in part to a very interesting, recent suggestion by Mike Oliver. Oliver, who introduced the social model of disability in 1983, wrote ‘Surely it is time to either re- invigorate the social model or replace it with something else’ (Oliver 2013, 1026). In Levitt (in press) I

responded to Oliver's suggestion that the social model be re-invigorated, and here I respond to his suggestion that it be replaced. I am not seeking to replace the social model. However, in this article I am seeking to complement it with a model that provides understanding of some aspects of disability that are not included in the social and medical models.

Background

I changed the name of my model to 'active' close to the completion of this article. I discarded my previous choice, 'empowered', as I do not accept that the actions of disabled people are necessarily any more empowering than removing their societal barriers or treating their disabling condition. The adjective 'active' was chosen, in order to convey that disabled people, through their own actions, can play an active role in reducing the effects of their own disabilities. I do not want to give the impression that I consider the model itself to be active; the word 'active' merely refers to the approach adopted by disabled people.

This article addresses an omission from the inclusion of disabled people, in that no current model focuses on the effects of the actions of disabled people on disability. Inclusiveness has been a major concern for disabled people, writers on disability and disability activists. For example, Oliver and Barnes (1997, 813) wrote 'As disabled peoples' demands to be included in all aspects of life become more vociferous, specific areas like disability research will have to address these issues more systematically than they have up to now', and Barnes and Mercer (2010, 98) wrote 'Campaigns by disabled people since the 1960s have highlighted their wide-ranging social exclusion and denial of basic citizenship rights.' In addition, Charlton (1998, 17) wrote '*Nothing about us without us* requires people with disabilities to recognize their need to control and take responsibility for their own lives.' Moreover, Forber-Pratt and Aragon (2013, 2) wrote 'There is a history of the voice of people with disabilities being silenced in discussions about disability.'

Mercer (2002, 228) wrote 'The alternative conceptual framework for understanding disability that emerged in the 1960s and 1970s shifted attention to the ways in which a "disabling society" rather than individual impairments contributed to the exclusion of disabled people from everyday social life.' I argue that, not only society, but also the actions of disabled people, can contribute to the inclusion of disabled people in social life. Forber-Pratt and Aragon (2013, 2) wrote 'The social model of disability posits that disability exists due to society's failure to remove social, economic, and environmental barriers.' I contend that the effects of disability can be decreased, not only by removing societal barriers, but also by effective action by disabled people.

Hughes, Goodley and Davis (2012, 310) wrote that the social model's practical mission is 'to dismantle the barriers that blocked disabled people's participation in society.' A goal of the active model is for disabled people to complement society in the task of limiting the effects

of disability. I argue that the constraints of disability would be combatted particularly well, if disabled people and others in society were to work together to reduce their impact.

The social, medical and active models can interact, in that more than one of their components (society, the disabling condition and the actions of disabled people) can simultaneously affect a person's disability. The concept of the interaction between factors that affect a person's disability has been expressed by writers on disability. For example, Smart and Smart (2006, 30) referred to the 'interaction' in disability 'between the individual and his or her environment and functions', Samaha (2007, 1251) wrote that the social model 'relates a person's disadvantage to the combination of personal traits and social setting', and the WHO (2017, webpage) referred to 'the interaction between features of a person's body and features of the society in which he or she lives.'

The active model of disability is timely, as several developments, over the last two decades, have substantially increased the potential for disabled people to reduce the constraints of their own disabilities. One recent development is a reduction in societal barriers to disabled people. Another recent development is the rapid growth in the number of disability support groups and more effective assistive technology. In addition, the Internet, through transforming the extent to which knowledge and experience can be shared, provides unprecedented opportunities for disabled people to understand and address their disabilities. Moreover, social media provides new opportunities for self-help and for collective disability activism.

These recent developments have substantially increased the scope for disabled people to limit the effects of disability. A major motivation for developing the active model is that I wish to foster greater awareness of the potential for many disabled people to reduce the constraints of their own disabilities. However, I do realize that the potential to decrease these limitations can be severely restricted by factors beyond the disabled person's control and that very many people cannot limit the effects of their own disabilities.

Disabled People in Current Models

Johnston (1997, 307) referred to a psychological model of disability that encompasses 'the psychological and emotional consequences' of disability. Swain and French (2000, 569) proposed an affirmative model (also called 'affirmation model') as 'a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle and life experience of being impaired and disabled.' In addition, Smart and Smart (2006) described an environmental model that focuses on the environment of disabled people (and on their relationship with it), and a functional model that concentrates on the functional performance (and limitations) of disabled people. Samaha (2007, 1251) included the 'personal traits' of disabled people within the social model. Moreover, Koppers (2009, 223) suggested a rhizomatic model 'that can hold

a wide variety of experiences and structured positions in moments of precarious productive imbalance.’ Recently, Bolt (2015, 1105) recommended a happiness-related model ‘based on a conceptual distinction between ableism and disablism.’

Models of disability have included the social identities of disabled people (the affirmative model) and the personal traits of disabled people (Samaha’s description of the social model). But, no model has included the effects of the actions of disabled people on disability. That is the focus of the active model.

Effects of Self-Help, Support Groups and Assistive Technology

Self-help is in keeping with the philosophy of the disability movement (Devlieger 1995). In addition, Scott and Doughty (2012) argued that within the disability movement the concepts of empowerment, choice and control have been developed as alternatives to the concept of care, and the peer-support movement in the mental health sector draws from this tradition. Moreover, Aglen, Hedlund, and Landstad (2011) found that most of the research on self-help and support groups for people with long-lasting health problems or disability was targeted towards improving the professional healthcare system.

Studies found that self-help can alleviate health problems and disability. For example, self-help contributed towards pain reduction (Kruger et al. 1998, Lefort 2000, and Carpenter et al. 2012) and towards the treatments of tinnitus (Konzag et al. 2006), of sub-threshold depression (Morgan and Jorm 2009) and of systemic lupus erythematosus (Chuang, Lin, and Gau 2010). However, the effectiveness of self-help can vary from person to person: Buenaver, McGuire, and Haythornthwaite (2006) discovered significant differences between people in the effects of cognitive behavioural self-help on the management of chronic pain.

Research reported self-help to be particularly effective when guided by health professionals. For example, the support of a clinician increased the effectiveness of self-help in the treatment of obsessive-compulsive disorder symptoms (Kenwright et al. 2005), the guidance of nurses in self-help was an effective way of treating patients with chronic fatigue syndrome (Wearden et al. 2006), and physiotherapy combined with self-help was conducive to increasing physical activity in people with multiple sclerosis (Mulligan et al. 2013).

Studies established that support groups can reduce the impact of disability. For example, the level of social interaction was higher amongst disabled students, who received peer support (Carter et al. 2005), or when peers provided academic and socially-related support to severely disabled adolescents (Carter et al. 2011). In addition, self-help centres assisted people who had psychiatric disability (Swarbrick 2006), and peer support decreased the likelihood of psychiatric hospitalization (Landers and Zhou 2011).

Research reported the effectiveness of combining self-help with support groups. For example, self-help and mutual help groups reduced the disempowering consequences of strokes

(Oiwah 1997), and membership of support groups was associated with diabetes patients more effectively managing their symptoms and blood sugar levels (Fisher et al. 2012).

Studies referred to the widespread use of assistive technology. For example, 60% of 1,414 disabled people reported using some form of assistive technology in their daily lives (Carlson and Ehrlich 2006) and the majority of carers of children with physical disabilities reported the use of assistive technology in the children's daily activities or routines (Kling, Campbell, and Wilcox 2010). In addition, Borg, Lindstrom, and Larsson (2011) reported that the literature on the use of assistive technology in developing countries was dominated by product-oriented research on leg prostheses and manual wheelchairs.

Research found that assistive technology can decrease the effects of disability. For example, assistive technology helped individuals aging with a disability to maintain valued activities and experiences (Kemp 1999), and computer technology aided disabled children in their education and play activities (Chantry and Dunford 2010). In addition, children with physical disabilities mentioned that assistive technology increased their self-confidence and productivity (Carpe et al. 2010), and disabled people who used assistive technology in school were more likely to participate in post-secondary education (Bouck, Maeda, and Flanagan 2012). Moreover, literature reviews identified that assistive technology reduces some of the physical and emotional effort entailed in supporting disabled individuals (Ben Mortenson et al. 2012) and that modern technology has the potential to increase independence and to decrease the costs of efficient care (Sestic et al. 2012).

The Active Model of Disability

The active model encompasses all actions of disabled people that affect disability. The previous section provides empirical support for the model, in that self-help, support groups and assistive technology were all found in several studies to limit the effects of disability. This empirical support justifies including self-help, support groups and assistive technology in the active model. Moreover, disability activism is also part of the model, as activism encompasses actions of disabled people and has helped change attitudes towards disability.

My description of the research on the effects of self-help, support groups and assistive technology contains findings relevant to the understanding of the active model. For example, the variation in the effectiveness of self-help supports the assertion that there are major differences between disabled people in the extent to which they can limit the impact of their own disabilities. In addition, the finding by several studies that self-help is particularly effective when combined with the support of health professionals indicates that the actions of disabled people can be much more effective when they are assisted by others. Moreover, the increased effectiveness of self-help when combined with support groups indicates that components of the active model can interact; I elaborate on this in the Discussion.

I argue that the responsibility for reducing the effects of disability rests with all of us, including society, health professionals and disabled people. I contend that the constraints of disability could be alleviated particularly well if we all work together to reduce its impact. I am not suggesting that disabled people are especially responsible for reducing the constraints of disability. Combating these constraints is a shared responsibility.

There are many ways in which disabled people can reduce the impact of their own disabilities. For example, they can use a combination of self-help, support groups and assistive technology to reduce the constraints of disability. They can develop positive mental attitudes to disability and can give priority to activities that are less affected by their disabilities. In addition, they can implement actions that overcome societal barriers to them achieving their aspirations. Moreover, they can modify their actions in ways that decrease the extent to which their disabling condition impinges on their aspirations. Finally, they can take the same actions as non-disabled people to overcome obstacles to their aspirations.

Discussion

My assertion that the actions of disabled people can decrease the impact of their own disabilities is consistent with my first-hand experience of severe visual impairment: I have found over the last three decades, that self-help, support groups and assistive technology have each alleviated at times the effects of my disability. It is also consistent with my social contact, over the past two decades, with visually impaired people: I find it striking that the actions of disabled people sometimes seem to play a larger role in determining the impact of their disabilities than societal barriers do or the severity of their disabling conditions. This observation convinced me that the actions of disabled people can substantially reduce the impact of disability.

The active model differs substantially from other models of disability, in that it alone focuses on the actions of disabled people. However, some models do focus on other aspects of disabled people. For example, Samaha's description of the social model encompasses disabled people's personal traits; the affirmative model focuses on their social identities, the environmental model concentrates on their relationship with their environment, and the psychological model focuses on the psychological and emotional consequences of disability.

In the previous section I asserted that components of the active model can interact. One example is when groups help disabled people to use assistive technology more effectively. Another example is when assistive technology enables disabled people to become aware of the self-help activities that are particularly suited to reducing the impact of their disabilities. A final example is when disabled people use self-help to identify the support groups from which they can particularly benefit.

Self-help encompasses learning from other disabled people. For example, newly disabled people can learn from long-term disabled people useful ways of adjusting to their disabilities. In addition, disabled people can share understanding on effective measures for overcoming societal barriers. Moreover, they can learn from the experiences and approaches of high-achieving disabled people.

The effectiveness of a support group may depend very much on how it is administered. Stewart et al. (2001) found that not only member control of the discussions, but also the selection, training and support of the group leaders to be important components of successful support groups for elderly disabled people.

The recent growth in the usage of assistive technology for some disabilities has been primarily in the use of computers. Palmer et al. (2012, 402) wrote 'Although the use of computers for individuals with intellectual and developmental disabilities is more prevalent, other technology use frequency is much the same as in the late 1990s.'

Some models of disability have been expressed in a way that seems to exclude the possibility of the actions of disabled people affecting disability. For example, Bolt (2005, 539) wrote 'The Social Model of Disability holds that persons are impaired for a number of reasons, but that it is only by society that they are disabled.' The phrase 'only by society' could imply that disability is solely shaped by society. In order to avoid implying that disability cannot be affected by factors outside of society, I suggest the wording 'The social model of disability focuses on the impact of society on disability.'

Applications of the Active Model

Johnston (1997, 309) recommended 'we identify the shared and cohesive strands of models.' A major similarity between the social and active models is that both models encompass the effects of the actions of people on disability (the effects of the social model are indirect: people's actions affect society, and the model focuses on the effects of society on disability). Because of this similarity, the applications of the active model resemble those of the social model.

Oliver (2013, 1025) wrote 'I have never seen the social model as anything more than a tool to improve peoples' lives.' The social model has improved disabled people's lives, through helping to reduce societal barriers. I argue that the active model can also improve disabled people's lives, through helping to increase understanding of effective ways in which disabled people can reduce the constraints of their own disabilities.

Barnes (2013, 42) wrote 'To be truly emancipatory, disability research must be empowering. It must generate accessible data that have meaningful and practical outcomes for disabled people' and Mercer (2002, 245) wrote 'The emancipatory paradigm has been adopted as a distinctive approach to doing disability research. This encompasses its ontological and epistemological location in a social

model of disability.’ I agree with the importance of disability research generating data that has practical outcomes for disabled people, but I disagree that emancipatory disability research needs to be located in, or even associated with, the social model. The active model can also foster emancipatory research. For example, it can motivate research that generates practical information on particularly effective ways in which disabled people can limit the effects of their own disabilities.

Goodley (2013, 55) wrote ‘The social model of disability holds potential for the inclusion of all disabled people.’ I realise that the social model has contributed much to the inclusion of disabled people, and argue that the active model can also contribute to their inclusion. Exclusion can be combatted, not only by removing societal barriers, but also by the effective action of disabled people.

Llewellyn and Hogan (2008, 320) wrote that models of disability ‘can aid understanding of disability in both research and clinical settings.’ I contend that models of disability, including the active model, can facilitate the understanding of disability for a wide range of people. This includes not only those in research or in clinical settings, but also those assisting disabled people, friends, relatives and colleagues of disabled people, and disabled people themselves.

I suggest that the active model could stimulate practical research on the effects of the actions of disabled people on disability. One example of this research is to understand how self-help can be made more effective. Another example is identifying the types of assistive technology that disabled people have found to be especially useful. A further example is assessing how newly disabled people could learn from the experiences of long-term disabled people. A final example is to understand how the collective actions of disabled people (including disability activism) could become more effective at addressing the concerns of disabled people.

Conclusion

I return to the World Health Organisations’ description of disability quoted in the Introduction: ‘a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives’ (WHO 2017, webpage). In this article I have contended that, factors in addition to the disabled person’s body and society, can strongly affect disability and have presented support for my assertion that the actions of disabled people can have a major impact on disability.

I have argued that the impact of disability can be shaped by a combination of society, the disabling condition, the actions of disabled people, and miscellaneous other factors. Attributes of the disabling condition that affect disability include the nature of the condition (e.g., whether visually or mobility impaired) and its severity. ‘Miscellaneous other factors’ include family support, level of affluence of the disabled person, and the speed and age of onset of the disability. I use the word ‘factors’ rather than ‘models’, as these items seem less central to disability than the social, medical and active models. However, it is possible that if assistive technology were to develop very much further it could have a sufficiently large impact on disability to be classified as a model.

I have contended that models of disability overlap, in that aspects of more than one model can concurrently affect a person's disability. An example of the overlap of the active and social models is support groups helping disabled people overcome societal barriers; an example of the overlap of the active and medical models is assistive technology enabling disabled people to reduce the constraints of their disabling condition. Moreover, I have suggested that the relative impact of society, the disabling condition, and the actions of the disabled person can vary substantially between geographical regions, from person to person, and over time in the same disabled person.

I have argued that, as the social and active models both encompass the effects of the actions of people on disability, the applications of the active model resemble those of the social model. In particular, the active model can motivate emancipatory research, and provide practical data that can improve the lives of disabled people. I am keen for the active model to be a stimulus to research on ways in which disabled people could manage disability more effectively. In the previous section I have suggested some examples of research that can be motivated by the active model.

The current generation of disabled people has substantially more opportunities to reduce the impact of their disabilities than previous generations of disabled people. Reasons for this include the reduced societal barriers to disability, more ubiquitous access to know-how for self-help, more widespread availability of disability support groups, and more effective assistive technology. I do hope that the active model of disability will encourage more disabled people to proactively seek to decrease the effects of their own disabilities. I urge all relevant parties, including disabled people and those associated with them, work together to reduce the impact of disability.

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